Talking to Your Child:

Initiating a Conversation to Disclose Your Brain Tumour Diagnosis

A Parent, Guardian and Caregiver's Guide

Developed in collaboration with:

McGill | Ingram School of Nursing

braintumour foundation OF CANADA | LA FONDATION canadienne des tumeurs cérébrales

For additional information, please visit BrainTumour.ca

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Please note this guide was designed by McGill University nursing students in collaboration, with Brain Tumour Foundation of Canada. Although we strive to ensure the information is accurate, ethical and credible, please let us know if we have inadvertently missed any details you think could be important.

Talking to Your Child: A Conversation Guide

When a parent, guardian or caregiver is diagnosed with a brain tumour, it can impact the entire family. Talking to a child about your diagnosis can be challenging, and it is completely normal to feel stress or anxiety about having these conversations.

Our goal is to support you every step of the way in finding the means to communicate your diagnosis to your child.

Take your time, go at your own pace and know that not everything has to be said all at once.

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Your nurturing, caring and supportive parenting or guardianship helps to ensure a healthy development in your infant or toddler's wellbeing. Understanding what to expect and listening to their unique cues can help you support them through their early years of growth and development.

At this age, your infant or toddler may:

- **Experience difficulty comprehending what they cannot see or touch.**
    - Since your diagnosis is not a physical object, it makes it difficult for your infant or toddler to understand.
- **Recognize that you are ill and may pick up on your emotional reactions.**
    - May notice that you have a 'boo-boo' on your head, or that you are losing your hair.
    - May see that you are spending time in bed or laying down.
    - May pick up on difficult feelings that you may be experiencing, such as sadness, worry or fear.
- **Fear separation and feelings of abandonment.**
    - May throw a 'tantrum' or cry when you leave the room.
    - May show signs of 'clinginess' out of fear you won't return (i.e. won't let go of your hand, won't let you put them down).

Even small changes to routine or surroundings can result in confusion and/or agitation, as well as altered sleeping and eating patterns. Emotions such as sadness, fearfulness, discomfort and anger may be apparent and can be seen through your infant or toddler's behaviour and vocabulary.

You may find it useful to refer to the feelings chart below when discussing emotions.

INFANTS AND TODDLERS

0 - 3 Years of Age

Coping with Reactions

Infants and toddlers may react to physical changes or noticeable side effects of your diagnosis or treatment, such as frequent vomiting, not being able to play or not being present as often as they are used to. Your infant or toddler may not be able to express how they feel in words and may rather may show you how they feel through their actions and behaviour.

At this age, your infant or toddler may:

- Feel afraid, angry or sad;
- Cry more easily and be difficult to comfort;
- Struggle with their usual sleeping and/or eating routine;
- Seek out more frequent physical contact (i.e. breastfeeding, hugging);
- Isolate themselves or hide away in certain areas of the house;
- Have a decreased appetite;
- Show less interest in activities that typically bring them joy and happiness;
- Suspect that something is wrong with their environment or with you;
- Worry, become more dependent and act out of character at home or at daycare;
- Show signs of regression when they are under stress (i.e. thumb sucking or wetting the bed);
- Experience separation anxiety and may refuse to leave your side.

You are encouraged to:

- Provide more physical contact (i.e. skin-to-skin time, hugging, cuddling);
- Listen to calming music together;
- Try gentle baby massages;
- Use the feelings chart to help them express their emotions;
- Provide reassurance in response to their emotions.

It is normal to feel like you are in a difficult position.

Be sure to reach out to a health-care provider who can guide you in how to respond to their current behaviour, or help you seek support.

INFANTS AND TODDLERS

0 - 3 Years of Age

Helpful Tips for Communication

WHO

- Although an infant or toddler may not remember these conversations, it is likely that you will. Be in the present moment.
- Another parent or spouse, as well as friends and family members, can be a good means of additional support. You may also wish to seek out assistance from a psychologist, child behavioural therapist or social worker to help develop effective communication skills.

WHAT

- When explaining symptoms, treatment effects and/or other aspects of your diagnosis to an infant or toddler, be sure to use simple terminology and language they will understand.
- Provide information in small doses and short sentences, and focus on disclosing what is happening presently, rather than what could happen in the future.
- Use picture books and toys to help describe what you may be experiencing. Local libraries and bookstores can be a useful resource.

WHEN

- Follow their lead (i.e. "more cuddles please").
- Arrange for quiet time that best suits the infant or toddler with minimal distractions.
- Try to avoid these interactions prior to naptime and/or bedtime.
- If you are caring for more than one infant or toddler, you may wish to speak with them separately so that you may tailor the conversation to their unique needs.

WHERE

- Find a place where you are most comfortable and the environment is safe.
- You may choose to initiate the conversation during a routine family activity such as sitting together on the couch, or playing a game in the living room.

WHY

- Hiding the truth from your infant or toddler can do more harm than good. They may imagine the worst if they are not told otherwise.
- Keeping secrets may teach your toddler that it is okay to hide information, which can develop into an untrustworthy relationship with you.

HOW

- Think about what you would like to say by either writing it down or rehearsing a dialogue.
- Try to keep the infant or toddler near you or another trusted adult to ensure support and consistency in their routine.
- If you are in the hospital, you may ask a caregiver or family member to help the infant or toddler speak with you over the phone or call you over video chat so they can be reassured that you are okay.

There are various ways to discuss your diagnosis with an infant or toddler.

Use the method that works best for you and your family.

INFANTS AND TODDLERS

0 - 3 Years of Age

Family Resources and Support

As a parent or guardian living with a brain tumour, you may often face challenging and stressful situations.

Having access to a network of supports can make a difference in how your infant or toddler will adjust to you being unavailable.

- Grandparents, close relatives, friends or neighbours can be incredibly helpful in keeping a consistent routine.
- Speaking with a nurse, social worker, clergy member or other supportive professional can be beneficial, as they may be aware of additional community resources and helpful tools such as picture books or animated videos.
- Communicating with your infant or toddler's daycare teacher and keeping them informed of your health trajectory can foster better care for your infant or toddler.

211.ca

211.ca is an informative resource within Canada that can provide you with additional supports and services, and allow you to engage with others who may be going through a similar experience.

Maintaining Family Dynamics

It is normal to feel like the disclosure of a brain tumour diagnosis could change the dynamic of your household.

Here are some suggestions to try and help maintain a healthy family dynamic during an often difficult time.

- Be flexible as circumstances arise, but try to stay consistent with rules and routines. Your infant or toddler will need to know that you are still their parent, even if you are unwell. Infants and toddlers thrive on consistency within their schedule, as it provides them a sense of safety and security.
- Continue to spend time with your infant or toddler, even if it is just sitting on the floor and colouring, or watching TV.
- Try to have one parent or caregiver spend quality time with them every day.

PRESCHOOL CHILDREN

4 - 6 Years of Age

Developmental Milestones

Your nurturing, caring and supportive parenting or guardianship helps to ensure a healthy development in your preschooler's wellbeing. Understanding what to expect and listening to their unique cues can help you support them through their early years of growth and development.

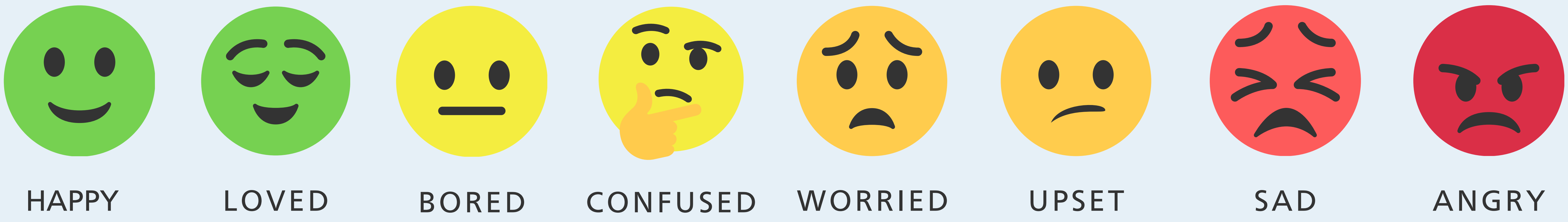
At this age, your preschooler may:

- Have a basic understanding that you are ill; however, some concepts may be difficult to grasp (i.e. the complexity of the illness, treatment regimes, etc.);
- Focus mainly on their immediate environment;
- Think of everything as in relation to themselves;
- Think or believe that they could 'catch' cancer, as they struggle to understand that some illnesses can be contagious, while others are not;
- Wonder if this particular illness is a result of something they have done wrong (i.e. misbehaving or having a negative thought).

It can be helpful to use tools, such as picture books or short stories, when having these conversations. There are lots of books with content that is age-appropriate for preschoolers. Check out your local library or bookstore.

A brain tumour diagnosis can be a stressful time for everyone in the family. Although your preschooler may have a basic understanding of feelings and emotions, they may have difficulty expressing their feelings about your diagnosis.

You may find it useful to refer to the feelings chart below when discussing emotions.



PRESCHOOL CHILDREN

4 - 6 Years of Age

Coping with Reactions

A preschooler's reaction to a parent's illness is most likely to be centred around themselves.

At this age, your preschooler may:

- Feel afraid, angry or sad;
- Cry more easily and be difficult to comfort;
- Struggle with their usual sleeping and/or eating routine;
- Seek out more frequent physical contact (i.e. hugging, cuddling);
- Isolate themselves or hide away in certain areas of the house;
- Have a decreased appetite;
- Show less interest in activities that typically bring them joy and happiness;
- Suspect that something is wrong with their environment or with you;
- Worry, become more dependent and act out of character at home or at daycare;
- Show signs of regression when they are under stress (i.e. thumb sucking or wetting the bed);
- Experience separation anxiety and may refuse to leave your side.

You are encouraged to:

- Allow your preschooler to express their feelings, even if it is difficult for them to do so;
- Provide reassurance that it is normal for them to feel sad, angry or worried about your wellbeing;
- Comfort them and explain that none of what is happening is their fault. The illness was not caused by anything they did or didn't do;
- Explain that the illness is not something that they can 'catch,' like a flu or a cold.

If you feel overwhelmed, ask for help.

If you are having difficulties with your child's adjustment to your diagnosis, you are strongly encouraged to seek support from a health-care professional.

PRESCHOOL CHILDREN

4 - 6 Years of Age

Helpful Tips for Communication

WHO

- It is okay to reach out to others if you are having difficulty disclosing your diagnosis to your preschooler on your own. Lean on a family member, friend or other relative for support.
- You may also wish to seek out assistance from a psychologist, child behavioural therapist or social worker to help develop effective communication skills.

WHAT

- You are the expert in knowing your preschooler's personality and behaviours. Feel free to use these traits to guide your discussion.
- Ask your child what they know about brain tumours, if anything at all.
- Tell your child about the potential physical side effects that may occur as a result of treatment (i.e. hair loss, nausea and vomiting, fatigue, or even your emotional state).
- Explain what is happening in relation to how it will affect them personally.

WHEN

- Although it can be tempting to delay the conversation, try to tell your preschooler as soon as you feel physically and emotionally able to.
- Consider initiating the conversation at a time when they are most likely to be attentive.
- Avoid sharing this news before bedtime or naptime, as it may affect their sleep.
- Provide them with your undivided attention, and answer all of their questions as best you can. You don't have to have all of the answers.

WHERE

- Find a place where you are most comfortable and the environment is safe.
- You may choose to initiate the conversation during a routine family activity such as sitting together on the couch or playing a game in the living room.

WHY

- Hiding the truth from your preschooler can do more harm than good. They may imagine the worst if they are not told otherwise.
- Delaying the conversation may teach your preschooler that it is okay to hide information, which can develop into an untrustworthy relationship with you.

There are various ways to discuss your diagnosis with your preschooler.

Use the method that you and your family are most comfortable with.

HOW

- Try to use simple words that your preschooler is already familiar with (i.e. "The doctors said that mommy has a bump on her head and they will have to look after me for some time").
- Your preschooler may need sufficient time to absorb the information. Let them initiate further discussions and ask questions. Follow their lead as they engage in the conversation.

PRESCHOOL CHILDREN

4 - 6 Years of Age

Family Resources and Support

As a parent or guardian living with a brain tumour, you may often face challenging and stressful situations.

Having access to a network of supports can make a difference in how your preschooler will adjust to your diagnosis.

- Grandparents, close relatives, friends or neighbours can be incredibly helpful in keeping a consistent routine and addressing difficult behaviours.
- Speaking with a nurse, social worker, clergy member or other supportive professional can be beneficial, as they may be aware of additional community resources and helpful tools such as picture books or animated videos.
- Communicating with your preschooler's teachers and childcare staff can foster better care for your preschooler.

211.ca

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Maintaining Family Dynamics

It is normal to feel like the disclosure of a brain tumour diagnosis could change the dynamic of your household.

Here are some suggestions to try and help maintain a healthy family dynamic during an often difficult time.

- Be flexible as circumstances arise, but try to stay consistent with rules and routines. Your preschooler will need to know that you are still their parent, even if you are unwell. Preschoolers thrive on consistency within their schedule, as it provides them a sense of safety and security.
- Continue to spend time with them, even if it is just sitting on the floor and colouring or watching TV.
- Try to have one parent or caregiver spend quality time with them every day.

PRE-ADOLESCENT CHILDREN

7 - 12 Years of Age

Developmental Milestones

Your nurturing, caring and supportive parenting or guardianship helps to ensure your child's healthy development. Understanding what to expect, listening to them and answering their questions can help you support their growth and development.

At this age, your pre-adolescent child may:

- Be able to understand certain aspects of the illness (i.e. treatment options, the type of cancer and affected body part);
- Recognize that you may have to go to the hospital more often;
- Observe and comment on side effects;
- Ask a lot of questions and demand immediate answers;
- Anticipate the future and what that may look like for you;
- Struggle to express emotions or distress;
- Be afraid that something they say or ask could upset you;
- Potentially overhear the term 'brain tumour' and its significance from a relative, on TV, on the internet or at school before you even have a chance to speak with them;
- May feel that they caused the illness by poor behaviour.

It can be helpful to use tools, such as books or animated videos to explain how the diagnosis may affect your child. Check out your local library or bookstore for age-appropriate content for pre-adolescents.

"What should I do if my child asks me if I am going to die?"

- Be honest and know that it is completely normal not to have all of the answers.
- If you don't feel comfortable addressing this question, we strongly recommend talking to your health-care team for additional tips and resources.

PRE-ADOLESCENT CHILDREN

7 - 12 Years of Age

Coping with Reactions

Young adolescents can respond to difficult news in a manner that may be physical, emotional or both.

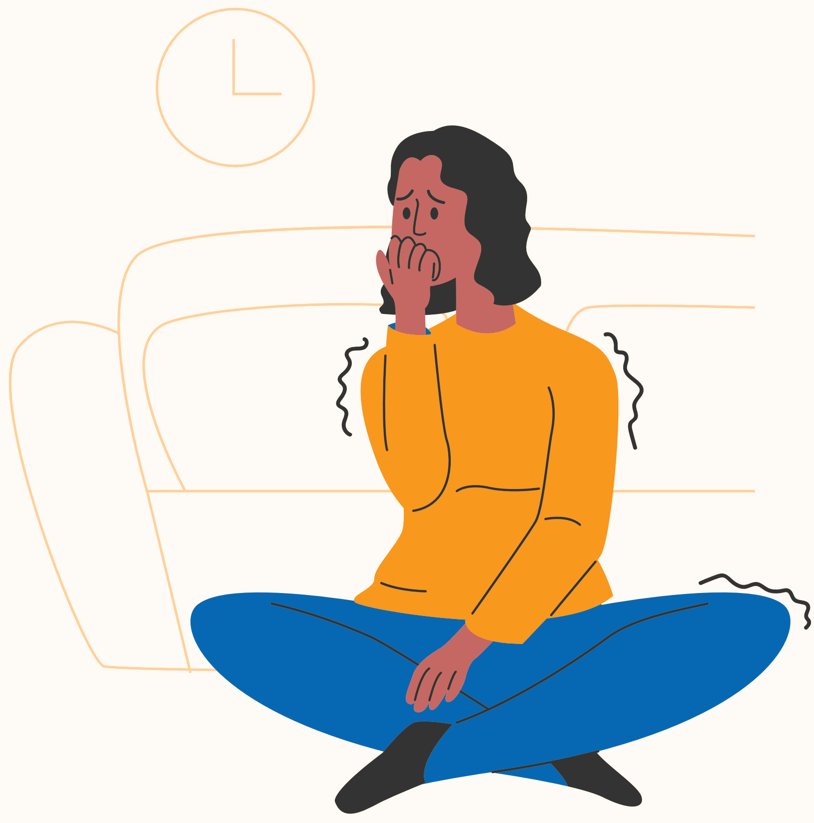
At this age, your pre-adolescent child may:

- Become more dependent and/or act out of character;
- Worry, especially about you leaving them or dying;
  - May ask you if you are going to die when you disclose your diagnosis;
- React to the physical side effects and changes that occur as a result of the diagnosis or treatment, such as hair loss, vomiting, fatigue, etc.;
- Be sensitive to the way that others react, including their siblings;
- Have an emotional response to you or their environment;
  - May become more anxious or frightened;
  - May cry out of feelings of guilt or sadness;
  - May experience a negative impact on their self esteem;
  - May become more irritable, and may yell or scream out of frustration;
- Experience difficulty concentrating and paying attention;
- Be afraid or refuse to attend school for fear that you will be gone when they return;
- Withdraw from family and friends as they struggle to adapt to change.

You are encouraged to:

- Be honest. Tell the truth about your diagnosis and give them a chance to ask questions.
- Be patient, and validate their fears and concerns.
- Provide reassurance that they did not cause the illness with their thoughts or behaviour and that they cannot 'catch' it.
- Communicate with the child's teachers, coaches and other close community members so that support can be provided as needed to help your child cope and adjust.
- Support your child in continuing to be involved in teams, social groups and extracurricular activities.

If you feel burnt out, seek support.



If your child is having difficulty accepting the news of your diagnosis, we encourage you to reach out to a member of your medical team.

PRE-ADOLESCENT CHILDREN

7 - 12 Years of Age

Helpful Tips for Communication

WHO

- It is okay to reach out to others if you are having difficulty disclosing your diagnosis to your pre-adolescent on your own. Lean on a family member, friend or other relative for support.
- You may also wish to seek out assistance from a psychologist, child behavioural therapist or social worker to help develop effective communication skills.

"We will try our best to be here for you, but sometimes grandma or grandpa may come over to help us."

WHAT

- Your child may want to know everything about your illness, but it's important to go at your own speed.
- Consider discussing the details in increments to allow time for your child to reflect on the information.
- Take some time to think about what you would like to disclose and speak to them at a level they will understand.
- Be honest and explain that while there is no way to know what is going to happen in the future, you will do your best to be as open and transparent as possible.

WHEN

- It is normal to wonder whether you should disclose the diagnosis as soon as you are told, or wait for more details regarding results and treatment. We advise you to tell them as soon as possible, or as soon as you feel able.
- Take the time to tell your child about your diagnosis when you are feeling calm, and try to avoid having this conversation before school or bedtime, as it can cause difficult emotions.
- Try to speak to them when they are engaged in an activity, such as drawing or playing a game.

There are many ways to communicate your diagnosis to your pre-adolescent child.

Begin the discussion when you are comfortable and calm.

WHERE

- Arrange for quiet time together where there will be minimal to no disturbances.
- Going for a walk or drive may also help facilitate a conversation with them.
- Provide your child with a safe space for them to be able to express themselves freely.

WHY

- Hiding the truth from your pre-adolescent child can do more harm than good. If they believe something is being kept from them, they may feel confused and afraid.
- Without adequate information to make sense of the current situation, they may fill in the gaps with their own imaginations.
- They may start asking questions, which could prompt the initial conversation.

HOW

- Try to use words they will understand (i.e. "I have a brain tumour. The doctors are giving me medication to help me feel better. Sometimes, it will make me feel sick or tired, but other times I will feel okay."
- You may have to repeatedly explain certain concepts, definitions or details about the illness.
- Listen to and observe your child for changes to their health and wellbeing.

PRE-ADOLESCENT CHILDREN

7 - 12 Years of Age

Family Resources and Support

As a parent or guardian living with a brain tumour, you may often face challenging and stressful situations.

Having access to a network of supports can make a difference in how your child will adjust to your diagnosis.

- Have a grandparent, relative, close friend or other trusted adult spend quality time with your child on a regular basis to help ensure they feel acknowledged and cared for.
- Encourage your child to stay involved in sports, clubs, groups and other extra-curricular activities to help them stay in touch with friends.
- Speak with a nurse, social worker, clergy member or other supportive professional as they may be aware of additional community resources, local programs and helpful tools.
- Communicate with your pre-adolescent's teachers and coaches to help foster better care for your child.

211.ca

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Maintaining Family Dynamics

It is normal to feel like the disclosure of a brain tumour diagnosis could change the dynamic of your household.

Here are some suggestions to try and help maintain a healthy family dynamic during an often difficult time.

- Try to maintain structure and a consistent routine in your child's day.
- If certain changes are expected to occur in the household (i.e. such as a change in routine), help your child cope by informing them in advance and talking about what will be expected.
- Support your child in having fun despite your illness to ensure they do not feel any guilt towards it.
- Suggest your child phone you, call you on video chat, or check in over text on a daily basis while you are away to help them feel connected to you.

ADOLESCENT CHILDREN

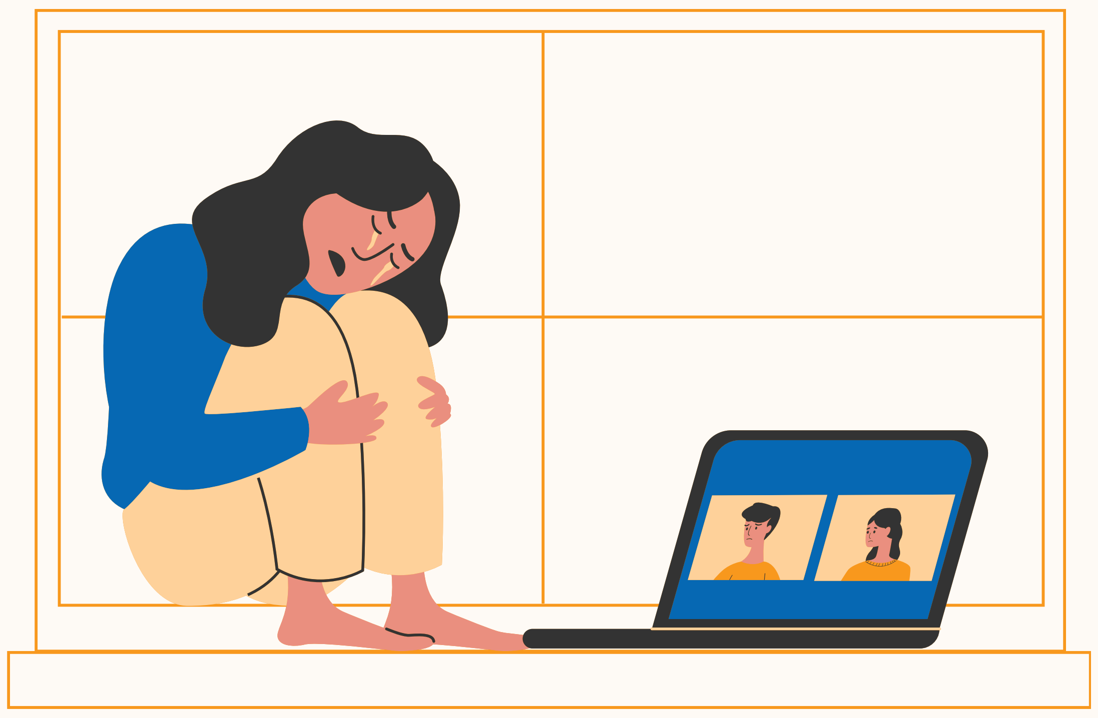
13 - 17 Years of Age

Developmental Milestones

Your nurturing, caring and supportive parenting or guardianship helps to ensure your child's healthy development. Understanding what to expect, listening to them and answering their questions can help you support their growth and development.

At this age, your adolescent child may:

- Be able to understand the complexities of a brain tumour (i.e. current diagnosis and symptoms, treatment plan and side effects);
- Recognize and interpret cause-and-effect relationships (i.e. how your illness results in the symptoms you present with);
- Act out of character, especially if they are finding it difficult to communicate their thoughts and feelings about your diagnosis;
- Isolate themselves from friends and family;
- Try to protect you from their feelings and emotions by attempting to hide or deny their anger, sadness or fears;
- Anticipate the future and what that may look like for you;
- Present with an increased level of maturity and wanting to take on additional responsibilities within the family;
- Worry about having less time to interact with you and other family members.



It's okay to not be okay.
You are not alone.

If you, your child or anyone in your family is struggling to cope, please talk to your health-care professional.

Your adolescent may cope with the news of your diagnosis by devoting more of their time to school work, taking part in activities and hanging out with friends.

ADOLESCENT CHILDREN

13 - 17 Years of Age

Coping with Reactions

Adolescents can respond to difficult news in a manner that may be physical, emotional, or both. Their reaction may also depend on how the information is relayed to them and their prior knowledge of the illness. Their behaviour may vary while they try to balance friendships, activities and staying close to their ill parent.

Your adolescent child may:

- Want to become more independent and treated like an adult;
- Worry about their loved ones dying or that they may become ill themselves;
- Fill in any gaps with assumptions and their imaginations if not enough information is provided to them;
- Develop a sense of insecurity and/or dependence on you or another caregiver;
- Regress to behaviours typical of a younger developmental stage (i.e. requesting to sleep next to their parent, watching children's TV shows);
- Criticize any support offered by caregivers or other adults;
- Prefer to confide in friends rather than family or siblings, and may act as if friends are more important than the rest of the family;
- Feel depressed, anxious, angry, rebellious or may hide their feelings;
- Have poorer judgement and may be inclined to take part in risk-taking behaviours such as substance use or food restriction.

You are encouraged to:

- Talk with your child about any changes to their behaviour.
- Talk with your child about their feelings, however, they may prefer to talk to friends.
- Show affection to let them know you love and care for them.
- Stay invovled with their activities and friendships to the best of your ability.
- Arrange opportunities for counselling or other types of therapy to help with difficult emotions and behaviours.
- Reassure them that it is normal to have these feelings and encourage them to learn how to respond and cope in healthy ways.

If you observe your child having difficulty accepting the news of your diagnosis, we encourage you to reach out to a member of your medical team.

Don't be afraid to ask for help.

ADOLESCENT CHILDREN

13 - 17 Years of Age

Helpful Tips for Communication

WHO

- It is okay to reach out to others if you are having difficulty disclosing your diagnosis to your adolescent on your own. Lean on a family member, friend or other relative for support.
- You may also wish to seek out assistance from a psychologist, child behavioural therapist or social worker to help develop effective communication skills.

WHAT

- Give detailed information about your condition, including symptoms and side effects.
- You may wish to include your adolescent in a way that they feel part of the discussion or allow them to partake in small decisions being made.
- Discuss any possible role changes within the family, but avoid having expectations for them to take on additional responsibilities.

WHEN

- It is normal to wonder whether you should disclose the diagnosis as soon as you are told, or wait for more details regarding results and treatment. We advise you to tell them as soon as possible, or as soon as you feel able.
- Take the time to tell your adolescent about your diagnosis when you are both feeling calm and comfortable. Try to avoid having this conversation before school or bedtime, as it can cause difficult emotions.

WHERE

- Arrange for quiet time together where there will be minimal to no disturbances.
- Going for a walk or drive may also help facilitate a conversation.
- Provide your adolescent with a safe space for them to be able to express themselves freely.

WHY

- Hiding the truth from your adolescent can do more harm than good. If they believe something is being kept from them, they may feel confused and afraid.
- Without adequate information to make sense of the current situation, they may fill in the gaps with their own imaginations.
- They may start asking questions, which could prompt the initial conversation.

HOW

- Be open, honest and clear in your explanations, and answer their questions to the best of your ability.
- Provide some basic knowledge of the diagnosis, if appropriate, including details about treatment and side effects.
- Keep them informed of any changes to your diagnosis, treatment plan, etc., especially with regards to how these changes will affect their day-to-day activities.

"I have a brain tumour. This means that something is growing inside my head that is not supposed to be there. I may have to have an operation to remove it. I may also have to go through some treatments to help me feel better. Do you want to ask me any questions?"

Give your child time to share their feelings and ask questions; it is OK if you do not have all the answers.

Reach out to a member of your medical team with any questions you or your child may have.

ADOLESCENT CHILDREN

13 - 17 Years of Age

Family Resources and Support

As a parent or guardian living with a brain tumour, you may often face challenging and stressful situations.

Having access to a network of supports can make a difference in how your child will adjust to your diagnosis.

- Have a grandparent, relative, close friend or other trusted adult spend quality time with your adolescent on a regular basis to help ensure they feel acknowledged and cared for.
- Encourage your adolescent to stay involved in sports, clubs, groups, and other extra-curricular activities to help them stay in touch with friends.
- If a supportive network does not exist within their environment, you may wish to speak with a nurse, social worker, clergy member or other supportive professional about resources that are available to them.
- Communicate with your adolescent's teachers and coaches to help foster better care for your child.

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Maintaining Family Dynamics

It is normal to feel like the disclosure of a brain tumour diagnosis could change the dynamic of your household.

Here are some suggestions to try and help maintain a healthy family dynamic during an often difficult time.

- Adolescents require attention, guidance and care to encourage healthy growth and development. Take the time to make dinner together or play a board game to connect, learn, and have some fun.
- Adequate support, a positive learning environment and being involved in leisure activities are key factors to help your child develop a strong sense of self.
- Check in regularly with your adolescent or arrange for assistance from a trusted adult to help address any concerns your child may have.
- Although their may be changes to roles and responsibilities, try to maintain a sense of consistency where possible.

We would like to extend our most sincere thanks and appreciation to:

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Please note this guide was designed by McGill University nursing students in collaboration, with Brain Tumour Foundation of Canada. Although we strive to ensure the information is accurate, ethical and credible, please let us know if we have inadvertently missed any details you think could be important.

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